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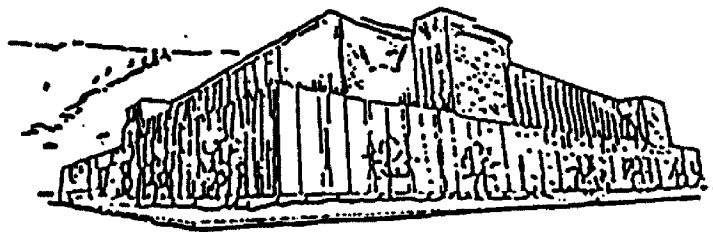
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END STAGE RENAL DISEASE PROGRAM EVALUATION

Prepared for

The Montana Department of Health and Human Services

Health Policy and Services Division

By

Amanda Schulster

B.S. Montana State University, 1996

presented in partial fulfillment of the requirements

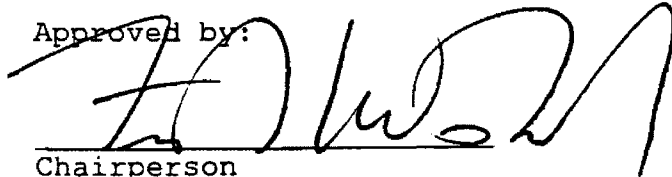
for the degree of

Master of Arts

The University of Montana

1998

Approved by:



Chairperson



Dean, Graduate School

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PREFACE

I am pleased to submit, on behalf of The ESRD Program, this evaluation. This report gives voice to the growing incidence and easily dismissed problem of chronic kidney failure. When I embarked on this endeavor I was unaware of where it would take me. It has been a journey and I am grateful for the opportunity it has afforded me.

I would like to express appreciation to the following people for their expertise and support throughout this work: Fred Reed and William McBroom, The University of Montana; Dave Thorsen and Gary Rose, Department of Public Health and Human Services, State of Montana; Carole Turner, St. Patrick Hospital Dialysis Center; and Thomas D. Bordelon, Northern Rockies Kidney Center.

I am particularly obliged to all the people with End-Stage Renal Disease and their families who gave me their time and shared a part of their lives with me. To the extent that this work has a dedication, it is to them.

My family, also stood behind this work. If not by their support for it then certainly by their presence and encouragement while it was being written.

Amanda Sehulster

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EXECUTIVE SUMMARY

~This report is the result of The Department of Public Health & Human Services through the Health Systems Bureau and the Financial Operations and Support Services Bureau contracting with The University of Montana to perform an evaluation of the End-Stage Renal Disease (ESRD) Program.

~This report is based on more than 20 face-to-face, in-depth interviews conducted with transplant, hemodialysis and peritoneal dialysis patients. Additional subjects interviewed were hospital and clinical financing administrators and personnel as well as family members of ESRD patients.

~The ESRD Program is limited by having only \$100,000 per year. Funding amount remains the same as when the program was established twenty years ago.

~Original intents of The ESRD Program are not being met. The legislative intent was to insure a program for the care and treatment of persons suffering from chronic renal disease but who are unable to pay for the services on a continuing basis.

~Patient counts are increasing at 10% per year and medical and health care costs have accelerated at approximately twice the rate of general inflation. At present The ESRD Program assists only 26% of the population that qualify. Patient funding is always exhausted half way through the fiscal year and funds ran out earlier this year than in any year in the past.

~Recommendations: #1) The Montana legislature needs to appropriate more money to provide assistance to its citizens suffering from failed kidneys. #2) Prioritize of narrow categories of services covered so as to warrant wholesale purchase of drugs and subsequent saving to The ESRD Program participants. #3) Prioritize eligibility requirements so that The ESRD Program patient's interests take precedence over those of the health care providers.

INTRODUCTION

The twentieth century has seen miraculous achievements in the conquest of disease and the extension of the life span. Despite living in the world's wealthiest nation, with the most dramatic and successful medical technologies, we have more than 20 million people suffering from kidney and urologic disease. Even with the most dramatic treatment modalities of kidney transplantation or hemodialysis, there continues to be an increase in the morbidity and mortality related to End-Stage Renal Disease (ESRD). The burden in terms of illness, death disability, quality of life and costs of health care and lost productivity is immense.

Montana has approximately 650 people living with failed kidneys. The ESRD Program was established in 1975 to provide assistance to those individuals suffering from failed kidneys. Funding was \$200,000 for the 1976-77 biennium. Since then, the rate of increase in real resources spent for the treatment of ESRD has been small, 2.3%-2.1% per year. Simultaneously, patient counts are increasing at 10% per year and costs for medical and health care services are accelerating faster than that of general inflation. At present, the State of Montana ESRD Program provides the same appropriations as in 1975 and assists only 26% of the population that qualify for the program. No administrative funds are available for this program and

patient funding is usually exhausted about half way through the state fiscal year.

GOALS AND METHODS

This evaluation is designed to assess the adequacy of service delivery in all modalities and treatment settings in Montana and make recommendations toward the improvement of the ESRD Program. Rather than using a statewide survey and its empirical strengths, the level of information sought herein is of a more penetrating nature. More than 20 face-to-face, in-depth interviews were conducted with transplant, hemodialysis and peritoneal dialysis patients. This in-depth interview method allows for a unique perspective on the ESRD Program. There is a degree of control with the interview process not available by survey questionnaire methods. The ability to use detailed questions in addition to open-ended and probe questions allows for qualitative as well as quantitative assessment. Additional subjects interviewed included a nephrology nurse, a nephrology social worker, a dialysis unit technician, a volunteer aid, an account executive for a distributor of dialysis equipment, spouses and family members of ESRD patients as well as hospital and clinic financing administrators.

The interview format focused on patients knowledge of the ESRD Program and the impact it has had on their

individual lives. Health insurance coverage and other methods of payment were also addressed. Other topics included patients' financial situations, their relationships with health care providers and any difficulties they have encountered with ESRD patients sponsorship. Because of the impact on patients' health, their emotional and spiritual conditions were also discussed.

The majority of patients interviewed were male and on hemodialysis, 60% and 75% respectively. Fifteen percent of individuals interviewed use peritoneal dialysis, while the remaining 10% were kidney transplant patients. Ninety-five percent of patients interviewed were from Missoula or the surrounding area and one patient was from Billings.

SUMMARY OF INTERVIEW RESULTS

Knowledge of The ESRD Program

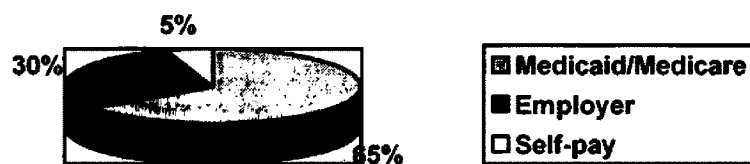
Of ESRD patients interviewed, 66% were unaware of the existence of the ESRD Program, 22% had some knowledge of the ESRD Program and 11% were aware of the program and its general purpose. Of those with knowledge of the ESRD Program, 75% responded that they had received that information from a social worker and one person had been informed by the dialysis unit director. Those stating they were unsure of the existence and nature of the ESRD Program believed any awareness must have come during the informative

stage at the time of their initial ESRD diagnosis. It was not clear whose responsibility it was to inform patients about the ESRD Program.

The consensus surrounding the ESRD Program was one of good-will. Of those interviewed with any knowledge about the ESRD Program there was a general sense that it provided an important contribution for a vulnerable population.

Insurance Coverage and Financial Assistance

Primary Insurance Coverage



Sixty-five percent of all ESRD patients interviewed had Medicaid/Medicare as their primary insurance provider. These clients' medical claims were routinely processed by their health care and insurance providers. Bypassing of patients during claim processing seems to contribute to the lack of knowledge about the ESRD Program. This group of patients had an unclear knowledge of their coverage and payment amounts and were uncertain when asked for precise figures. However, all of these clients reported receiving

requests from Medicaid/Medicare regarding verification of services rendered by providers.

Of the remaining seven ESRD patients interviewed, those with private/employer insurance coverage, only one had used ESRD Program assistance. Of those respondents never using ESRD services all reported knowing people in greater need of financial assistance than themselves. They reported being "fortunate" and "lucky" that they were not in need. Further, they reported feeling there was a great need for the services offered by the ESRD Program and that the availability of such funding was insufficient.

Only one patient interviewed, with private/employer insurance coverage, reported having actually used the ESRD Program assistance. This ESRD patient had full knowledge of the ESRD Program, describing exact amounts and services covered. Also, this patient related specific dollar amounts of medical and pharmaceutical expenditures he would be held accountable for until the 1998 fiscal year begins and more ESRD Program funding is available. This patient gave a detailed account of the extent to which it was necessary for his family to sacrifice to remain solvent. Although this is a double income family, and they live in a home and lifestyle well below the average for the Missoula area, they are apprehensive and fearful of the future months without the ESRD Program assistance. This family foregoes any extra

expenses such as "going to the movies" or "eating out" in an effort to remain self-supporting. They pay health insurance premiums of \$306 per month and their out-of-pocket expenses for drugs are approximately \$466 per month. Regardless of the limitations of the ESRD Program this patient expressed appreciation for the assistance received. Despite the economic hardship, this patient and family endure they reported being grateful that eligibility standards allow them to participate while they still have a few material resources. This allows this family a degree of autonomy and dignity not available were they to exhaust all personal resources and rely solely upon public assistance.

Another patient, who had just recently experienced the expiration of his employer insurance coverage, was now relying totally upon public assistance. This patient reported that if he were held responsible for the claims the ESRD Program was now covering his family would no longer be able to pay their household utilities. This patient was appreciative and proud that the household bills were current despite the adverse conditions the family had suffered.

The Unavailability of ESRD Program Funds

Thirty percent of ESRD patients interviewed have never used ESRD Program assistance and so were unable to address that line of questioning. However, when asked if they

perceived a need for the Montana legislature to provide more financial assistance there was an unanimous "Yes." All of these patients, although not needing or using the ESRD Program assistance, were emphatic about the inadequacy of resources for many people suffering failed kidneys.

The majority 70% of ESRD patients interviewed, those depending upon public assistance, try various methods in an attempt to obtain the care and treatment they need. Those ESRD patients dependent solely upon public assistance are the most impoverished. The debt and destitution incurred by these people is hardly alleviated by the assistance provided by the ESRD Program. Approximately one half of patients interviewed fell into this category.

Impoverished ESRD patients living independently are deprived of the basic necessities of life. It is not uncommon for them to live without an automobile, telephone, television, medical treatment, supplies or sufficient food, heat and warm clothing. ESRD patients characteristically suffer from fatigue, weight loss and weakness. Maintaining a comfortable body heat was consistently reported as problematic. Lack of sufficient clothing, insufficient heating resources during the winter months and inability to stay warm while in the dialysis unit was frequently reported.

About half of the patients on public assistance cited obtaining adequate amounts of protein in the diet as problematic. All of these patients stated they have gone without recommended dietary requirements at some time because they lacked the money to purchase them. Sixty percent of these patients had gone without prescribed medications due to lack of money. One ESRD patient interviewed explained how to "beg and bum" for needed medicine from the centers and doctors when "free samples" are no longer available. Additionally, medicine that was still not used at the time of death of one ESRD patient had been passed on and utilized by other patients. Although both patient and provider knew this practice was illegal it is not an uncommon practice.

Another commonly reported theme was the practice of "living simple," gardening, fishing, hunting and bicycling as a means of managing scarce resources. The cost of incidentals and "hidden expenses" were cited as causing financial, as well as emotional, hardship.

When patients were asked if they were currently in debt as a result of ESRD related medical expenses the majority answered "yes" (80%). One patient, with employer group insurance, revealed that after nearly depleting a recent inheritance of \$10,000 he was no longer in arrears.

However, this reprieve was temporary as "the insidious indebtedness was mounting again."

Another common financial resource for ESRD patients is the family. Family dynamics are complex and beyond the scope of this evaluation. The financial aid most frequently accepted from families was shelter, and 20% of interviewed adults lived with siblings or their own children. These patients expressed gratitude and feelings of indebtedness and abasement. Another common form of financial aid accepted from family members was a one-time credit card advance or help with unexpected, relatively large, unforeseen expenditures. These expenses were most often reported in the areas of housing, transportation or lodging costs.

Relationships with Health Care Providers and Perceptions of Services Rendered

Most (95%) of ESRD patients interviewed perceived their relationship with their dialysis unit staff, doctor and pharmacist as either "very good" or "great." Relations between dialysis patients and their health care providers are very different from the usual between health care professionals and clients. The inordinate amount of time dialysis patients and their medical care givers are required to spend together presents opportunities for discord. This

intensive interaction and heightened familiarity presents occasions for distress. The degree to which both the Missoula and Billings Deaconess dialysis units are praised by their own clientele, is impressive.

Both the Billings Deaconess and Missoula Providence Center dialysis unit managers were rated as "excellent" with one exception. The one dissenting opinion was reported by a patient who was new to the Missoula area and had previously lived out-of-state. This individual had been a patient at many different dialysis units and preferred all the other dialysis unit personnel and health care providers to the care received in this state. This patient complained that dialysis unit administration and rules prevented patients from participating in their own treatment. Patients could not weigh themselves or get their own blanket or pillow, tasks that permit autonomy and promote wellness. This patient felt dialysis unit staff often negated or ignored client input, treating patients impersonally.

Nephrologists and doctors from both areas were described as "good, nice, down to earth and deserving of respect." Pharmacies, too, were cited as "helpful, cooperative and understanding." Again, there was one dissenting opinion and it is included in this report because of its serious nature. One patient was denied prescribed medicine from a pharmacy, even though it was covered by

Medicaid, but because the patient could not pay the \$2-\$3 co-payment. However, after contacting several area pharmacies it was confirmed that this is not a common practice and those contacted would not deny lifesaving medication on those grounds.

Patients were also questioned about which areas (hospital bills, doctor bills, pharmacy bills, dialysis bills, or transportation) cause the greatest financial strain and there was no unified response. Notwithstanding, sixty percent responded by deploring the high cost of medical care. Common expressions about the prohibitive cost of medical services and supplies were, for example: "Where does it stop?" "\$1900 for medicine, what could it be?" "Outrageous!" "Why does it cost \$100 for a shot of insulin at the hospital but I can give myself a shot for \$1?"

A few patients complained of paying doctor bills after being treated by a nurse and never even seeing the doctor (15%). Even while consciously considering the attending physicians' overhead costs, these patients expressed dismay at the high prices charged for medical services and supplies.

Patients also reported dramatic variations in prices from one pharmacy to another. Several ESRD patients reported financial savings from comparison shopping and the majority of respondents (80%), patronize a particular

pharmacy for reasons motivated by price not services rendered. Another consistent finding was the problems with transportation. Transportation to and from the dialysis unit is provided free of charge by the local city bus, and was consistently reported as "good." A problem arose for those hemodialysis patients delegated to the last shift of the day. Often the city bus was no longer running when the patients finished hemodialysis treatment necessitating a taxi ride home. A taxi ride, three times per week, is a considerable expense, especially when living in poverty.

Related to these findings were problems with the expense of maintaining individual vehicles. Ten percent of ESRD patients had automobiles that they could not afford to maintain. One patient, with total disability, had received a wheelchair accessible van from a human resource organization. This vehicle had not been operated for several months because the patient could not afford repair costs. Another individual was in need of, and not financially able to purchase, tires for their vehicle. Winter weather exacerbated any problems ESRD patients had with transportation.

Emotional and Spiritual Aspects

It was indicated by more than half of those interviewed that emotional depression was a factor affecting their

overall health (60%). It is noteworthy that research shows there is a high degree of denial in patients with chronic renal failure regarding the gravity of their condition. ESRD patients characteristically minimize the degree to which the illness impacts their lives. Those patients denouncing any emotional difficulties frequently went on to divulge experiencing excessive or pronounced anger, loneliness and exhaustion.

Patterned means for dealing with these emotional difficulties emerged. "One day at a time" was the most commonly reported philosophy by which these ESRD patients lived (40%). Twenty percent reported that reflecting on "being better off than other people" or "grateful to be alive" allowed some freedom from despair. One person reported being "a better person after having lived life as a person dying of kidney failure."

Most patients reported using antidepressant medication at some time during their life (60%). All stated the effect of the drug was not significant or "did not help."

Eighty percent of patients interviewed spoke of death. The patterned manifestation of death in their lives was reported as episodic with instances of "wanting to give up." Most patients interviewed stated they were encouraged by family members to "hang on."

Having attachments, such as family, jobs, school, church, interests or goals as a focus, decreased the reported degree and incidence of depression. Another important means of dealing with emotional fatigue was exercise. Walking or riding bicycles was noted by 15% of patients interviewed as instrumental in relieving hopelessness.

The time most challenging to emotional stability cited consistently by ESRD patients was the months following the initial diagnosis of ESRD. Fifty percent said this was an extremely painful time. As patients waited to qualify for social security benefits, disability income, Medicaid/Medicare insurance, employee retirement plans, they experienced increasing dependency and powerlessness. Finances were especially tenuous at this time. Completing the necessary forms and applications, frequently several times, "changing and re-doing," and "jumping through the hoops" was characteristically frustrating, frightening and maddening. The anxiety surrounding the loss of control over their lives, the surrendering of their future hopes and plans, the indigence and role of being chronically ill made this a most vulnerable time. The process of acceptance of the chronic renal failure diagnosis and its prognosis was said to be excruciating.

Only a small percentage (15%) of patients acknowledged their spiritual beliefs as important in managing their lives. Five percent replied that their spiritual beliefs were "somewhat important," while 80% said although they might believe in a spiritual being it was not important in the care of their lives.

Discussion & Recommendations

General

Three main areas of the ESRD Program administrative rules are considered in this assessment summary: 1) funding appropriation, 2) covered expenses, and 3) eligibility requirements.

Discussion of Funding Appropriation

MONTANA SESSIONS LAWS CHAPTER NO. 453
(4/16/75)

An act to establish a program providing lifesaving treatment for chronic renal disease, requiring standards for determining eligibility to be established and appropriating two hundred thousand dollars (\$200,000) from the general fund for the biennium ending June 30, 1977, to the department of Social and Rehabilitation Services for such purpose.

Considering the increasing numbers of clients and costs of health care services coupled with the decrease in available resources more funding is paramount. The

appropriated funds do not seem to relieve the problems of ESRD patients.

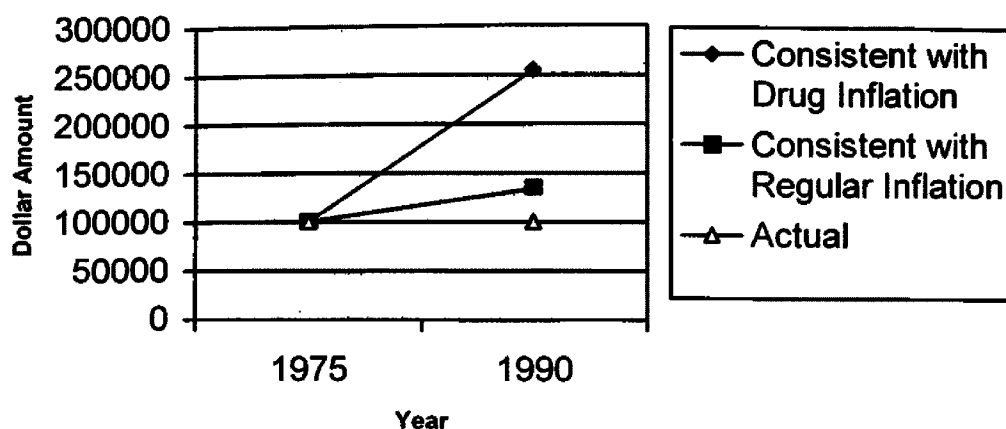
The rate of real resources spent for the treatment of ESRD often leaves patients in virtual desperation as they attempt to acquire life-saving treatments. While acknowledging the nearly inevitable indigence of most ESRD patients there is a broadening ideological speculation from both the Department of Public Health and Human Services as well as the ESRD population. That speculation is that it is only through governmental structures that these deficiencies in provisions can be confronted.

It is the purpose of this program to

“...provide treatment to persons suffering from chronic renal diseases, including dialysis and other medical procedures and techniques, which will have life-saving effect in the care and treatment of such persons.”

The original intent of the ESRD Program is not being met. In order to provide funding consistent with inflation and proportionate to that of the 1976 enactment law the Montana legislature would need to appropriate \$255,000 per year.

Appropriations



According to Bureau of Labor Statistics between 1975 and 1990 general inflation increased 135% and drug inflation increased 255%. More appropriations are needed to remain in accordance with original intents of legislation.

Furthermore, in the light of recent welfare reform and an increasingly recessive economy the quality of life for indigents is worsening. With only one quarter (26%) of the possible qualifying population presently enrolled in the ESRD Program and available funds consumed in the first of the fiscal year, the scarcity is great. More and more of Montana residents with chronic renal failure are living on less.

Discussion of Covered Expenses

MONTANA SESSIONS LAWS CHAPTER NO. 453
71-2502. Establishment of program. The department of social and rehabilitation services shall establish a program to provide treatment to persons suffering from chronic renal diseases, including

dialysis and other medical procedures and techniques, which will have a lifesaving effect in the care and treatment of such persons. The department shall extend financial assistance to persons suffering from chronic renal diseases in obtaining the medical, nursing, pharmaceutical, and technical services necessary to care for such diseases, including the rental or purchase of home dialysis equipment and supplies.

Categories of ESRD services currently reimbursed are broad. In consideration of the extraordinarily high per person expenditure for medical provisions, prioritizing the specific services provided by the ESRD Program would increase benefits for those individuals whom it assists.

There are many competing claims for these resources but according to administrative figures 60%-63% of all ESRD Program funds are disbursed to pay for drugs that Medicare/Medicaid does not cover. By limiting, or prioritizing covered expenses and concentrating claims on the specified area of drug procurement there is an opportunity for greater utilization of limited resources. The concentrated volume of a specified drug would make feasible the negotiation of a wholesale contract with local pharmaceutical providers. The competitive nature of this proposal would provide a direct and immediate saving to individuals purchasing medication.

Also, by prioritizing or narrowing the covered expenses there would be a simultaneous limitation of other services,

including large, lump sum payments. Resources would ultimately last longer and be more evenly disbursed throughout the eligible ESRD population. The final result would be a fairer more equitable distribution of scarce resources.

Discussion of Eligibility Requirements

MONTANA SESSIONS LAWS CHAPTER NO. 453
71-2502. ...The department shall establish standards in order that treatment shall be provided to those who are financially unable to obtain such treatment without causing severe economic imbalance in the family economic unit. Such standards shall be established without reference to maximum or minimum income levels.

ADMINISTRATIVE RULES OF MONTANA
16.35.101

(7) "Severe economic imbalance" means deprivation of the family unit of the necessities of life, caused by payment of expenses for the treatment of renal disease.

Both ESRD patients as well as health care providers expressed concern over eligibility criteria. Although some ESRD patients have incomes only slightly higher than allowable rates for qualification for governmental assistance their access to financial resources is actually less than for individuals who do actually qualify. ESRD patients, who are attempting to remain solvent and are striving to pay their bills, have a greater need for the

ESRD Program assistance. Their unpaid claims are their responsibility and they are held liable.

In contrast, many ESRD patients having Medicaid/Medicare as primary insurance carriers are indigent and considered "charity cases" or a business loss when their debt exceeds the approved coverage allowances and goes unpaid. When this happens the professional or institution absorbs the debt. Thus if the ESRD Program pays these claims the benefit is primarily to the institution or professional providing the service. The Medicaid/Medicare patients can disregard incurred debt with impunity. A greater service is accomplished by privileging the individual patient over the institution or professional.

Program Recommendations

Recommendation #1: The Montana legislature needs to appropriate more money to provide assistance to its citizens suffering from failed kidneys.

In order for the ESRD Program to be effective, legislative appropriation must remain at an amount proportionate to that established within the 1976 enactment. The original amount of funding was set at \$100,000 per year. Since that time there have been significant increases in patient counts and payment rates for medical services. The amount of appropriations needs to at least double in order

to accomplish the original intents of legislation.

Recommendation #2: Prioritize or narrow categories of services covered so as to warrant wholesale purchase of the drugs and a subsequent saving to the ESRD Program participant.

The greatest expenditure of the current ESRD Program is drugs not covered by other payers. By restricting reimbursement to this class of service a greater purchasing power is afforded with increased and immediate return for the ESRD Program participants.

Recommendation #3: Prioritize eligibility requirements so that ESRD Program patient's interests take precedence over those of the health care providers.

Currently the ESRD Program funds are spent on claims made by health care professionals and institutions, or claims that do not directly benefit individual clients. Preferential eligibility qualifications would provide a greater service in accordance with the intended purpose of the ESRD Program in helping individuals with renal disease.

APPENDIX

INTERVIEW QUESTIONS: END-STAGE RENAL DISEASE PROGRAM EVALUATION

Welcome and Introduction: Amanda Schulster, Sociologist/Researcher

General Information about Interview

Explanation of the Project & Purpose of Evaluation

- Health and Human Services Department interests
- Interviewer interests

QUESTIONS

- How did you first come into contact with the ESRD Program?
- Are ESRD benefits reaching those individuals that most need assistance?
- What do you perceive as the greatest benefits of the ESRD Program?
- What do you perceive as the greatest limitations of the ESRD Program?
- What impact does the ESRD Program have on your individual lives and/or households?

HEALTH INSURANCE COVERAGE

- Do you have health insurance?
- If you do have insurance, what kind of health insurance coverage do you have?
- Discuss the extent to which ESRD services are covered by other payers.
- Are there other financial assistance programs that you

use or that you are aware of that are useful specifically for end-stage renal disease patients? If so, what are those programs?

-Discuss how end-stage renal disease patients without health insurance coverage meet their needs and obtain necessary medical treatments?

-Have you been denied health insurance coverage or had a health insurance policy cancelled as a direct result of end-stage renal disease?

-Has the latest Welfare Reform affected the extent to which Medicare or Medicaid covers your ESRD medical expenses?

-Do you know of people with end-stage renal disease that have no means of paying medical bills? If so, do they continue to receive medical treatment and what difficulties do they encounter?

FINANCES

-Are you currently in debt as a direct result of medical expenses incurred in regards to end-stage renal disease?

-In which areas are your greatest medical expenses (for example hospital bills, Doctor bills, pharmacy bills, dialysis, and transportation)?

-Have you ever foregone medical treatment because of lack of finances?

-When the ESRD Program has no more money to assist you with medical claims, where do you turn for financial assistance?

-How has your financial situation, incurred as a result of chronic renal failure, affected you family and/or friends?

MISCALANEOUS QUESTIONS

-How would you describe your relationship with your medical providers (Pharmacy, Doctor, nurses, Nephrologist, communications, billing)?

-What difficulties do you have in the following areas regarding the ESRD Program: application procedures, time periods and constraints, documentation of claims, priority of claims/payments, notification of the end of ESRD benefits, treatment by Health and Human Services personnel, insufficient funding?

-Is there a need for the state legislature to provide more financial assistance than is currently allowed for those people suffering from chronic renal failure?

-What changes in the ESRD Program do you think would be most beneficial?

-Are there other areas of concern you would like to mention?